DOCUMENT RESUME

ED 385 074 EC 304 107

AUTHOR	Ort, Sharon I.; And Others
TITLE	Tourette Syndrome and the School Nurse. Revised.
INSTITUTION	Tourette Syndrome Association, Inc., Bayside, NY.
SPONS AGENCY	American Legion Child Welfare Foundation, Inc., Indianapolis, Ind.
PUB DATE	94
NOTE	25p.
AVAILABLE FROM	Tourette Syndrome Association, Inc., 42-40 Bell Blvd., Bayside, NY 11361-2874 ($3).
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Attention Deficit Disorders; *Drug Therapy; Elementary Secondary Education; Hyperactivity; *Neurological Impairments; *School Nurses; *Staff Role; Student Adjustment; *Student Behavior; Student Needs; *Symptoms (Individual Disorders)
IDENTIFIERS	Obsessive Compulsive Behavior; *Tourette Syndrome

ABSTRACT

Information on Tourette Syndrome (TS), as well as transient and chronic tic disorders, is provided in this pamphlet for the school nurse, who can support and educate the child, family, and other school personnel. Information is included on genetic factors and behaviors that may be connected to TS: obsessive-compulsive symptoms, hyperactivity, inattention, disruptive behavior, and learning disabilities. It is noted that some children with TS may require accommodations in the regular classroom, special classroom placement, or more rarely day hospital or residential placements. Possible roles of the school nurse include: reassuring the child who is confused or upset about the tics and the consequent teasing they may experience, helping teachers understand ways that TS can interfere in the classroom, assisting families to understand TS and to cope with their reactions, dispensing and monitoring medications for children who require them, and explaining medications to school staff and the family. Information is provided on types of medications that may be prescribed for children with tics, obsessive compulsive symptoms, and attention and hyperactivity disorders, including dosages and possible side effects. Brief annotations are provided on four videotapes and five publications. (SW)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☑ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED 385 074

TOURETTE SYNDROME AND THE SCHOOL NURSE

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

S. Levi-Pearl

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

by: Sharon I. Ort, R.N., M.P.H.
Lawrence Scahill, M.S.N., M.P.H.
Kimberly A. Lynch, M.S.N.

2

EC 304107

BEST COPY AVAILABLE

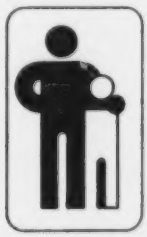
The Authors

Sharon I. Ort, R.N., M.P.H., Associate Research Scientist, Clinical Nurse Specialist, Yale Child Study Center, Lecturer, Dept. of Public Health, Yale School of Medicine.

Lawrence Scahill, M.S.N., M.P.H., Associate Research Scientist, Clinical Nurse Specialist, Yale Child Study Center, Assistant Clinical Professor of Nursing, Yale School of Nursing.

Kimberly A. Lynch, M.S.N., Clinical Nurse Specialist, Yale Child Study Center.

Tourette Syndrome Association is profoundly grateful for the generous support of this publication provided by:



American Legion Child Welfare Foundation, Inc.

Patrick

Patrick, a 9-year-old fourth grader, was brought into the school nurse's (Mary Jones) office to wash an abrasion on his face. He had been in a fight with another boy during recess. As Ms. Jones cleaned Patrick's face, she inquired about the fight. "Johnny called me a retard," Patrick said. "Why did he call you that?" Ms. Jones asked. "Because of my habits; I make faces, I blink my eyes, sometimes I jerk my arms. Johnny says I tried to hit him - I didn't."

As Patrick talked, Ms. Jones observed some of these movements. She noticed eye blinking, facial grimacing, shoulder jerks and tensing of his abdominal muscles. Patrick also sniffed and cleared his throat frequently. She wondered if he had a cold, if he had been crying, or perhaps these noises were tics as well. Ms. Jones sent Patrick back to class and decided to review his medical record. She also scheduled a meeting with Patrick's teacher.

The 4th grade teacher reported to Ms. Jones that she too had noticed Patrick's facial grimaces, arm movements and noises. In fact, she had moved him to the back of the room because he was unable to sit still and be quiet. He was falling behind in his assignments, and the teacher had just sent a note to Patrick's mother requesting a conference. She also recalled that Patrick had recently received a detention for fighting on the bus.

Tics & Tourette Syndrome

Tics are repetitive, involuntary movements or utterances that may be simple or complex. Simple motor tics involve brief, rapid movements such as eye blinking, facial grimacing and head jerking. Examples of simple phonic tics include throat clearing, grunting and snorting. Children may also exhibit more complex motor tics such as hopping, spinning or repetitive touching. Complex vocalizations may include repetitive phrases such as "wow", "honey", "oh boy." Sometimes tics occur in orchestrated bouts in which various tics happen in close succession.

Tic disorders are classified by the age of onset, duration of symptoms, and the presence of both motor and phonic tics. The available evidence suggests that tic disorders reside on a continuum from mild to severe, though additional research is needed to confirm this impression.

Transient tic disorder is characterized by one or more motor tics or phonic tics (but not both) that are present for a period of weeks to months and then disappear. The most common motor tics are eye blinking or other facial tics. Phonic tics may include throat clearing or snorting. Transient tics appear during the early school years and are usually mild with minimal interference in school performance or peer relationships.

Chronic tic disorder is differentiated from transient tics by duration in that either motor or phonic tics, but not both, are present for more than a year. Chronic motor tics are probably more common than chronic vocal tics and sometimes more noticeable. The presence of chronic motor or phonic tics does not necessarily herald the onset of Tourette Syndrome, but chronic tic disorders may be a manifestation of the same underlying vulnerability.

Tourette Syndrome (TS), which was first described by the French neurologist, Georges Gilles de la Tourette, is a more severe tic disorder characterized by the presence of chronic motor and phonic tics.

Some of the diagnostic criteria for TS include:

- Age of onset before the age of 18;
- Both multiple motor and one or more vocal tics present at some time during the illness, not necessarily concurrently;
- Tics occur on a daily basis, persist for at least one year with no tic-free periods of more than 3 consecutive months;
- The tic symptoms are the source of marked distress or significant impairment for at least three months.

– Diagnostic & Statistical Manual - Fourth Edition, American Psychiatric Association, 1994.

Although TS is appropriately regarded as the most severe of the tic disorders, it also demonstrates a wide range of severity. The number and frequency of symptoms may vary over time, with the social context and with the child's state. For example, tics may be inhibited in school or at a neighbor's house only to become very frequent as soon as the child arrives in the safe environment of home. Tics are generally worsened by life stress, fatigue and excitement. Curiously, focused activity usually results in a reduction of tics, but relaxing activities such as watching television can be accompanied by more tics. The average age of onset of tics is about seven years old with eye blinking, facial movements, head jerks, throat clearing or grunting being the most common early symptoms. These symptoms may vary in frequency from several a minute to several an hour. In its most severe forms, children may have near constant, forceful motor and phonic tics that occur in bouts. A small percentage of children with TS may make obscene vocalizations or gestures and, rarely, a few might manifest self-injurious behavior.

Tics are defined as involuntary. However, many children and adults describe an urge or a feeling of localized tension that precedes their tics. Children with TS often report that if they do not make a certain movement or sound, they will feel "weird," "uncomfortable," or as if they will "explode." Some children

develop elaborate means to camouflage their tics such as brushing hair from the face to mask a head jerking tic, dancing movements to hide spinning around, hitting themselves while performing a socially unacceptable act such as "giving the finger." Differentiating between complex tics, behavior intended to camouflage tics and impulsive behavior can be a challenge requiring careful discussion and clinical experience.

Epidemiology

Estimates of prevalence for transient tics, chronic tic disorder and Tourette Syndrome vary due to changes in the definition of TS, differences in data collection methods and the lack of large community samples. Transient tics appear to be relatively common in school-age children though accurate estimates are difficult to obtain. Estimates for chronic tics are in the range of 3-10% depending on the population studied. By contrast, the prevalence of TS has been estimated to be approximately 1 case per 1,000 for boys, 1 case per 10,000 for girls. The largest study to date was carried out in Israel with sixteen and seventeen year-old army recruits. The study considered past history as well as current symptoms for both boys and girls and found a prevalence of 1 case per 2,000 with boys being about two times more likely to have TS than girls. TS occurs in all social groups and across all racial and ethnic lines. Furthermore, despite previous impressions to the contrary, there is no convincing evidence that TS is more common in any particular ethnic or racial group.

Associated Behaviors

Obsessive-compulsive symptoms

In addition to motor and phonic tics, as many as 50% of children and adults with TS have recurring thoughts (obsessions) and/or repetitive habits (compulsions). In some cases, though certainly not all, these clinical features emerge after the onset of the tics and they can be quite distressing. Common compulsions include the need to arrange objects in rows

or patterns, repeatedly turning light switches on and off, tying and retying shoes and performing cleaning rituals. Children may report the need to repeat these behaviors until it feels or looks "just right." These compulsive behaviors may be as disruptive as the tics and may impair school performance. For example, a child might write and rewrite sentences in class, or go over the same letter so many times that assignments are not completed. In some cases, children become stuck in their repetitive behavior and are unable to move to the next activity until they get it "just right."

Obsessions can also be distressing for children with TS, and they may find it difficult to talk about their recurring thoughts. Some repetitive thoughts, such as the frequent intrusion of a certain song, a phrase or number sequence, can be a distracting nuisance to young people. More distressing are recurring thoughts of harm to one's self or family members from injury or illness.

Hyperactivity, inattention and disruptive behavior

Other common behavioral problems associated with TS in childhood involve the regulation of attention and activity. In clinic samples, approximately 50% of children with TS have difficulty concentrating, are distractible, impulsive and over-active. These familiar symptoms of Attention Deficit Hyperactivity Disorder (ADHD) often precede the onset of tics and may manifest in different combinations such that some children are primarily inattentive, while other children may be predominantly hyperactive or impulsive. When they occur, these behavior difficulties may overshadow tic problems.

Learning disabilities

Most children with TS have average intelligence. Nevertheless, some may have specific learning disabilities. Children with learning disabilities should be carefully assessed in order to identify the specific handicap and to design an appropriate educational program. Moreover, because learning disabilities often coexist with ADHD, some children with TS and a learning disability may also exhibit disruptive behavior. These children, like other children with ADHD, may require

additional structure in the classroom to ensure academic success. Also, they will need specific remediation for their learning problems. The extent to which these problems of learning and disruptive behavior are part of TS or merely additional problems is unclear and is a matter of ongoing research.

In summary, although many children with TS do quite well in a mainstream educational program, others may require special education services. Having TS can interfere with educational progress in several ways: direct interference from tics, intrusive thoughts and repetitive behaviors, symptoms of ADHD, and/or specific learning disabilities. Special educational services may consist of modest accommodations in the regular classroom, assignment of a teacher's aide, resource room assistance, placement in a special classroom setting, or, in rare cases, day hospital programs or placement in a residential facility.

Developmental Consequences

Children with TS often worry about the reactions of others to their tics, and some may become the object of teasing. Moreover, results from recent studies suggest that some children with TS may be overanxious prior to the onset of tics. Thus some children with TS may be predisposed to anxiety disorders. Those children who also have ADHD may have additional social impairment due to their impulsiveness and disruptive behavior. Given the potential for these negative social consequences, it is not surprising that some children and adolescents with TS may become anxious, tense and discouraged. Despite efforts to suppress them, the inevitability of tic expression may add to this discouragement. Academic failure may further erode the child's self confidence. Thus, as with other chronic conditions, the secondary problems of TS and the individual child's response to having the disorder may be as important as the disorder itself.

Etiology: Genetic and Epigenetic Factors

The cause of TS is unknown, but it appears to be due to a genetically transmitted vulnerability. TS is considerably more common in families with an affected member than in the general population. Secondly, twin studies have shown that identical twins, who have all of their genes in common, are far more likely to be mutually affected by TS than fraternal twins (who share half of their genes on average). Finally, careful analysis of the inheritance of TS suggests that it is transmitted as a single autosomal gene in a dominant pattern. Despite a decade of intensive research, this gene has not yet been found. Nonetheless, accumulated evidence from various sources suggests that the presumed inherited vulnerability results in a dysregulation in brain circuits that pass through the basal ganglia. These brain structures are known to be involved in the planning and execution of movement, and are also known to play a role in causing other movement disorders.

Although there is considerable evidence that TS is genetically transmitted as a single gene, this gene demonstrates a wide range of expression and actually may not express itself in some individuals who carry the gene. Indeed, the severity of TS varies greatly from one individual to another within the same family. This is also true among mutually affected identical twin pairs. Thus, it is clear that environmental factors also play a role in TS severity. These factors may include adverse perinatal events, exposure to CNS stimulants and perhaps stressful life events as well. Recent preliminary research has also raised the possibility that group A streptococcal infections may induce an exacerbation in tics. This intriguing hypothesis is in the early stages of scientific inquiry. Accordingly, conclusions about the role of immunologic processes in tic disorders must await further investigation.

Twin and family genetic studies also provide information regarding the relationship of TS, OCD and ADHD. Genetic research has supported the clinical impression that TS and OCD are related conditions. Not only is there an increased frequency of OCD in

relatives of individuals with TS, but OCD appears to follow the predicted pattern of genetic transmission. The genetic connection between TS and ADHD is less clear. Although ADHD does occur at higher than expected rates in the families of children with TS, that disorder does not appear to follow a simple genetic transmission pattern. Additional research may help to unravel the relationship of TS and ADHD.

The School Nurse as Clinician

Ms. Jones reviewed Patrick's school record which indicated that he was of average intelligence. Although there had been some concern about his academic performance in kindergarten, he was promoted to the first grade and has remained in regular classes since. His second grade teacher had reported excessive eye blinking and facial movements, but they were dismissed as "nervous mannerisms." Patrick occasionally received unsatisfactory reports for distractibility, inattention and disruptive behavior throughout his school years, but he had not demonstrated any serious conduct problems.

Patrick's medical record revealed that he was healthy with no history of major illness, serious injuries or hospitalizations. He had occasional bouts of otitis media which apparently responded to antibiotic treatment. His frequent eye blinking prompted a referral for an eye examination which was negative.

Ms. Jones contacted Patrick's mother to inform her of Patrick's abrasion and scuffle in the playground. She asked Patrick's mother whether she had noticed his movements and sounds at home. At that point Patrick's mother started to cry. She didn't know what was happening to her son - he was making all these noises and movements, fighting with everyone at home and on the bus, and she had recently received a note to confer with Patrick's teacher. Ms. Jones arranged a meeting with Patrick's parents on the same day as their meeting with his teacher.

Ms. Jones listened to the description of Patrick's symptoms and suggested that these "nervous manner-

isms" and behavioral difficulties could be part of a neurological disorder called Tourette Syndrome. She advised Patrick's parents to consult with their primary care practitioner who very likely would make a referral to a pediatric neurologist, child psychiatrist or developmental pediatrician. She also gave the family the address of the Tourette Syndrome Association to obtain additional free information.

The school nurse or nurse practitioner in a school-based clinic can play an important role in the identification of children with tic disorders. A child who is sent to the nurse's office for medication, or to a school-based clinic for assessment may provide the opportunity to identify a previously undetected tic disorder. For children who have already been diagnosed with TS, the school nurse can be an important resource for information about tic disorders and the medications used in the treatment of tics and related problems.

Children with TS may wonder why they have tics, if they are to blame for their tics, and whether the tics will ever go away. The nurse can provide reassurance that, in most cases, tics do get milder as the person matures into adulthood. Although it is difficult to predict which children will go on to have severe tic symptoms as they develop into adulthood, tic disorders are generally not progressive conditions. Even for children with severe TS in childhood, tics tend to change in number and frequency over time. One movement or vocalization will be replaced with others and previous tic symptoms may return. Although involuntary, tics can be voluntarily suppressed for brief periods of time. This feature of TS can be confusing to parents, teachers and children alike. Pointing this out to a child like Patrick can help him understand why his tics vary in different settings such as at school or at home. Stress, excitement and fatigue usually aggravate symptoms. Therefore, during tests or prior to a special field trip, the number and frequency of tics may increase. Vacation times such as summer recess may be accompanied by a reduction in symptoms.

Some children may need help coping with teasing from their classmates. The nurse in the school setting can listen to the child and discuss better adaptive responses than fighting to deal with the anger and pain of being teased. Being an accepted member of the group is important for all children, and this is especially true for children with TS. Involvement in extracurricular activities such as sports, marching band, chorus and drama club permits the child to be an active member of a group. The nurse can advocate for the child to ensure that he or she is not barred from these activities unnecessarily.

The School Nurse as Educator

Education of School Personnel

The school nurse is often relied upon as a health educator for teachers and other school personnel. For children such as Patrick, the nurse should inform teachers and perhaps Patrick's classmates about TS and the medications used to treat his symptoms. Once the teachers and students understand the involuntary nature of tics, they may amend their view of Patrick and no longer see him as a troublemaker.

The nurse might lead a discussion with teachers on the ways in which TS can interfere in the classroom. For example, a boy like Patrick may be expending a significant amount of energy just to control his tics, and have little remaining energy to learn his multiplication tables or geometry. Many children with TS have trouble with handwriting. In addition, hand or arm tics, or compulsive re-writing may further interfere with written work. Simple solutions such as the use of a tape recorder or computer can be helpful. The problems with handwriting or direct interference from tics often make test taking especially difficult for students with TS. Adolescents with TS may be at a considerable disadvantage when taking standardized tests such as the PSAT or SAT. Thus, in some cases, untimed testing should be considered. The educational team may also look to the school nurse to advise them concerning the impact of medication on academic progress. Clearly, the nurse in the school setting has a role to play in designing appro-

priate educational strategies and perhaps classroom placement for children with TS.

Education for Families

Families of children with TS often recount tales of misdiagnosis and inconclusive consultations. In such cases, the nurse may be able to help the family obtain an appropriate referral. When families learn about the genetic underpinnings of TS, some parents may also wonder if they are somehow to blame for their child's tics. Occasionally, families may reveal the presence of tics or related problems in other family members. For example, Patrick's father recalled that he had eye blinking movements and made various noises as a child, and stated: "You know, I still wrinkle up my face sometimes, but that's just to push up my glasses." Some parents may also have a current or past history of compulsive behaviors. Parents with tics or obsessive-compulsive symptoms may feel responsible for the child's problems. Some families may also need to express their guilt about having punished their child prior to understanding the involuntary nature of the motor and phonic tics. Recognition of these issues will enable the school nurse to be supportive to families and explain these complexities to other school personnel.

Medication

In most cases, children with TS do not require medication. However, if the tic symptoms interrupt intended activity, interfere with interpersonal relationships or school performance, medication is then considered. Some medications need to be administered during school hours in which case the nurse will see the child to dispense medication. This offers an opportunity to evaluate both the therapeutic and any adverse effects of the medication as well as the child's overall adaptation. Even in cases where medication is not dispensed in school, periodic monitoring by the school nurse can help determine whether the medication is effective and well tolerated. The field of child and adolescent psychopharmacology has greatly expanded in recent years, and there are a number of new agents used in the treatment of TS

and associated behaviors such as ADHD and obsessions and compulsions. The proliferation of these agents requires continued education for health care professionals including school nurses. Despite the promise of these new medications, they can have physical, behavioral and cognitive side effects. (See Table 1 for a summary of medications commonly used in the treatment of TS and related problems).

Neuroleptics

Medications such as haloperidol (Haldol) and pimozide (Orap) have been used in the treatment of TS for many years. These medications block the effect of dopamine in the brain and often achieve significant improvement in tic symptoms with small doses. Early in treatment there is a very small risk of an acute dystonic reaction in which muscles of the arms and neck stiffen, occasionally this can progress to oculogyric crisis in which the neck is craned to one side and the eyes roll upward. Anti-Parkinsonian agents such as benztropine (Cogentin) are used to treat these side effects and may be prescribed prophylactically early in treatment. More common side effects may include sedation, mood changes, depression, school phobia, motor restlessness, blurred vision, cognitive blunting and excessive weight gain. As with other neuroleptics, long term use of haloperidol or pimozide carries a small risk of developing tardive dyskinesia. Despite the fact that tardive dyskinesia is also a movement disorder, there is no evidence to suggest that children with TS are at any greater risk for developing tardive dyskinesia.

Direct comparison studies of pimozide and haloperidol suggest that they are equally effective in controlling tics, though doses of haloperidol are typically lower than pimozide. The side effects of these medications are also similar, though some clinicians believe that pimozide may be slightly better tolerated. On the other hand, there have been reports of cardiac arrhythmias with pimozide, hence cardiac monitoring may be included in the treatment plan of children on pimozide. Because of their potential for short and longterm side effects, these medications are typically avoided unless the tic symptoms are

prominent and interfere with daily living. Although there may be differences in clinical practice, the most common approach is to aim for moderate control of tics at the lowest possible dose.

Clonidine

Clonidine (Catapres) is an antihypertensive agent that is also used to treat TS. This medication acts on a different neurochemical system than the neuroleptics and may take two to three months to achieve a positive response. In general, clonidine is begun at low doses and slowly increased over several weeks. Side effects may include sedation, which is most evident when therapy is first initiated, but may occur later in treatment as well. Some children complain of dry mouth or headache and parents may report sleep problems and increased irritability. Surprisingly, blood pressure is rarely a problem. However, when discontinued, clonidine should be tapered slowly to avoid a rebound increase in blood pressure, tics and anxiety.

Stimulants & Antidepressants

Stimulants such as methylphenidate (Ritalin) are the most commonly used drugs in the treatment of ADHD. However, children with TS and ADHD who are treated with a stimulant may demonstrate an increase in the number, intensity and frequency of tics. Because ADHD often precedes the onset of tics, the tics may emerge following a trial of stimulant medication. Despite this chronology, there is no convincing evidence that methylphenidate *causes* a tic disorder. Moreover, although a few recent research studies confirm that stimulants can worsen tics in some children with TS, other studies suggest that some children with TS can tolerate stimulants without unacceptable increases in their tics. Further study is needed to characterize these subgroups of children with TS. In the meantime, many clinicians avoid the use of stimulants in children with tics while others may prescribe the stimulants and monitor the child closely for any change in tic symptom severity.

Tricyclic Antidepressants

Tricyclic antidepressant medications such as imipramine (Tofranil), desipramine (Norpramin), and nortrip-

tyline (Pamelor) are sometimes used as alternatives to the stimulants because they do not appear to worsen tics. Side effects of these medications may include dry mouth, dizziness, nausea and constipation. Tricyclic antidepressant medications can also increase heart rate and occasionally cause alterations in the electrical conduction through the heart. Hence, electrocardiograms are often used to monitor the cardiac effects of tricyclic antidepressants. Although it is not a tricyclic, buproprion (Wellbutrin) is another antidepressant that is sometimes used to treat ADHD.

Antiobsessional Agents

The introduction of antiobsessional medications over the past decade is a significant advancement in the psychopharmacologic treatment of TS and related conditions. As indicated previously, the co-occurrence of OCD and TS is common, and generally the medications used for tic symptoms are not helpful for treating obsessive-compulsive symptoms. Medications such as clomipramine (Anafranil) and fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil) and sertraline (Zoloft) are antidepressants that selectively block the reuptake of serotonin in the brain. This selective action apparently accounts for the therapeutic action because other antidepressants without this property are not effective in reducing obsessive-compulsive symptoms. Clomipramine is a tricyclic medication, hence its side effect profile is similar to the other tricyclics. Common side effects for the other available antiobsessional agents cited above are behavioral disinhibition, restlessness, nausea and diarrhea.

New Medications

In an effort to find new and better treatments for TS and associated problems, clinicians and researchers in various centers are testing new treatment strategies. Examples of new medications that school nurses may encounter include: guanfacine, deprenyl and risperidone. Guanfacine (Tenex) is similar in action to clonidine and has recently shown encouraging preliminary results in the treatment of inattention and impulsiveness in a small number of children with TS. Deprenyl (Eldepryl), which is a selective monoamine oxidase inhibitor that is used in the treatment of Parkinson's disease, has also shown

promise for the treatment of ADHD without causing an exacerbation of tics. Risperidone (Risperdal) is a newly approved neuroleptic medication that is chemically unrelated to either pimozide or haloperidol. Like pimozide and haloperidol, risperidone was developed for the treatment of schizophrenia. To date, risperidone has not been well studied in TS, but its mechanism of action and encouraging side effect profile have heightened interest in this medication for the treatment of tics. Much more study is needed to determine whether these new drugs are effective in the treatment of TS and related problems.

MEDICATION USED IN THE TREATMENT OF CHILDREN WITH ADHD & OCD

Generic Name	Brand Name	Starting Dose (Per Day)	Usual Dose Range	Possible Side Effects
Tricyclic Antidepressants:				
imipramine	Tofranil	10-25 mg	50-150 mg	Dry mouth, blurred vision, constipation, fatigue, EKG changes, weight gain
desipramine	Norpramin	10-25 mg	50-150 mg	Same as imipramine
nortriptyline	Pamelor	10-25 mg	50-125 mg	Same as imipramine
Antidepressants and Anti OCD:				
fluoxetine	Prozac	4-20 mg	5-60 mg	Restlessness, insomnia, stomach upset
paroxetine	Paxil	5-10 mg	10-60 mg	Same as fluoxetine
clomipramine	Anafranil	25 mg	50-150 mg	Dry mouth, blurred vision, constipation, fatigue, EKG changes, weight gain
sertraline	Zoloft	10-25 mg	75-200 mg	Fatigue, insomnia, restlessness, weight gain
fluvoxamine	Luvox	25 mg	50-200 mg	Same as fluoxetine

Attentional Stimulant Medications:				
methylphenidate	Ritalin	5-10 mg	10-60 mg	Headache, stomach ache, appetite loss, insomnia, irritability, increased tics
pemoline	Cylert	18.75-37.5 mg	37.5-150 mg	Same as methylphenidate
dextroamphetamine	Dexedrine	2.5-5 mg	5-30 mg	Same as methylphenidate

MEDICATIONS USED IN THE TREATMENT OF CHILDREN WITH TICS

Generic Name	Brand Name	Starting Dose (Per Day)	Usual Dose Range	Possible Side Effects
haloperidol	Haldol	0.25-0.5 mg	0.5-2.5 mg	Fatigue, weight gain, muscle rigidity, personality changes, tardive dyskinesia, school phobias, photosensitivity, depression
pimozide	Orap	1-2 mg	0.5-4 mg	Same as haloperidol, EKG changes
clonidine	Catapres	0.05 mg	0.1-0.25 mg	Fatigue, dry mouth, irritability, dizziness, headache, insomnia
clonidine patch	Catapres TTS	TTS 1 patch	TTS1-TTS3	Same as clonidine tablets, localized skin rash
clonazepam	Klonopin	0.5 mg	0.5-1.5 mg	Fatigue, irritability, dizziness, disinhibition

Summary

Tourette Syndrome is a neurological disorder characterized by motor and phonic tics, and in some cases, associated symptoms. Tic symptoms are chronic with a tendency to wax and wane in severity over time. Usually TS is not a progressive condition. Although the cause is unknown, dysregulation of brain circuits in the basal ganglia appears to be important in the pathophysiology of TS.

Research over the past two decades suggests that TS is a genetic disorder with a broad range of expression from mild to severe. The TS phenotype appears to include obsessive-compulsive symptoms. Problems with attention, impulsiveness, hyperactivity and anxiety regulation are common in clinical samples of children with TS, but it is not clear if these problems are part of TS or separate conditions.

Children with TS may be subjected to teasing by peers and, sometimes, disparagement by uninformed teachers and family members. Some require medication to help with their difficulties. The nurse in the school setting is in a unique position to monitor the child's condition and treatment response. The nurse can help school personnel to better understand the complexities of TS - especially with respect to which behaviors are part of the syndrome and which behaviors the child may be expected to control. Although this distinction may not be straightforward in some cases, careful discussion can usually lead to appropriate limit setting. In order to carry out this educational role, the nurse in the school setting must keep up with current knowledge about TS and its related conditions. This is especially critical regarding the medications used in TS treatment.

As with other chronic conditions, the child with TS often needs additional support and understanding. The student should be allowed, and indeed encouraged, to participate in school activities. In the process of monitoring the child's medication in the school setting, the nurse should also monitor the child's overall adjustment to having a chronic condition. The nurse may hear about teasing from classmates, apprehension about having tics during an upcoming school event, academic troubles, or fears of blurting out inappropriate comments in the classroom. Allowing the child to express these concerns may help to reduce their impact. In other cases, the school nurse can refer the child within the school or to outside health care providers. Thus, the school nurse can play an important role in the direct and indirect care of students with TS.

Sources for additional information

Krauss J. *Health care reform: Essential mental health services.* Washington, DC: American Nurses Publishing, 1993.

Psychiatric Mental Health Nursing Psychopharmacology Project. Washington, DC: American Nurses Publishing, 1994.

This publication is intended to provide information about Tourette Syndrome, its management and the medications currently in use. Families should be advised to first consult a physician concerning all treatments and medications.

TSA gratefully acknowledges the counsel and guidance of its Medical Advisory Board in the review of this publication. Members of the TSA Medical Advisory Board welcome queries from colleagues and other professionals and can be reached by contacting the Tourette Syndrome Association.

ADDITIONAL TSA RESOURCES

VHS FILMS

A Regular Kid, That's Me: An Inservice Film For Educators — A new aid for teachers to help understand the complexities of teaching children with TS. Includes explanation of the complexities of TS and suggests interventions that work.

Stop It! I Can't — For elementary school ages. Written to create sensitivity and reduce ridicule among their peers.

I'm A Person Too — Prize winning documentary featuring five people from diverse backgrounds talking about living with TS; depicts the broad range of symptoms.

Tourette Syndrome: The Parent's Perspective — Diplomacy in Action — Features E. Collins, Ph.D. and R. Fisher, M.Ed., providing guidance to TS families on school advocacy issues.

LITERATURE

Coping with TS — A Parent's Viewpoint — E. Shimberg. Covers parental and family acceptance, behavior management. (Revised 1993)

Problem Behaviors & TS — Drs. R. Bruun, and K. Rickler. Describes recent research and what is now known about the relationship of a variety of behaviors and TS. Contains helpful advice by Emily Kelman-Bravo, CSW, MS about the management of problem behaviors for families and individuals with TS. (Revised 1993)

Discipline and the Child with TS: A Guide for Parents and Teachers — R. Fisher-Collins, M.Ed., 1993. Helps children redirect impulses and compulsions through teaching cause and effect relationships. Included are techniques and disciplining children without the use of aggression or intimidation.

An Educator's Guide to Tourette Syndrome — S. Bronheim, Ph.D. Covers symptoms, techniques for classroom management, attentional, writing and language problems.

An up to date Catalog of Publications and Films, including prices, can be obtained by writing to:

TOURETTE SYNDROME ASSOCIATION, INC.
42-40 Bell Boulevard
Bayside, NY 11361
Tel # (718) 224-2999
Fax # (718) 279-9596

Tourette Syndrome Association, Inc.
42-40 Bell Boulevard
Bayside, New York 11361-2874
Tel: (718) 224-2999
Fax: (718) 279-9596

Permission to reprint this publication
must be obtained from the national office.

© TSA, Inc.

10M/Revised 1994